

## CHAPTER 2014-163

### Committee Substitute for Committee Substitute for House Bill No. 709

An act relating to Alzheimer's disease; amending s. 252.355, F.S.; requiring the Division of Emergency Management, in coordination with local emergency management agencies, to maintain a registry of persons with special needs; requiring the division to develop and maintain a special needs shelter registration program by a specified date; requiring specified agencies and authorizing specified health care providers to provide registration information to special needs clients or their caregivers and to assist emergency management agencies in registering persons for special needs shelters; amending s. 381.0303, F.S.; providing additional staffing requirements for special needs shelters; requiring special needs shelters to establish designated shelter areas for persons with Alzheimer's disease or related forms of dementia; authorizing the Department of Health, in coordination with the division, to adopt rules relating to standards for the special needs registration program; creating s. 381.82, F.S.; establishing the Ed and Ethel Moore Alzheimer's Disease Research Program within the department; requiring the program to provide grants and fellowships for research relating to Alzheimer's disease; creating the Alzheimer's Disease Research Grant Advisory Board; providing for appointment and terms of members; providing for organization, duties, and operating procedures of the board; requiring the department to provide staff to assist the board in carrying out its duties; requiring the board to annually submit recommendations for proposals to be funded; requiring a report to the Governor, Legislature, and State Surgeon General; exempting certain activities of the board from the Administrative Procedure Act; authorizing the department to adopt rules; providing that implementation of the program is subject to appropriation; amending s. 430.502, F.S.; updating the name of the memory disorder clinic established in Brevard County; requiring the Department of Elderly Affairs to develop minimum performance standards for memory disorder clinics to receive base-level annual funding; requiring the department to provide incentive-based funding, subject to appropriation, for certain memory disorder clinics; providing an effective date.

Be It Enacted by the Legislature of the State of Florida:

Section 1. Section 252.355, Florida Statutes, is amended to read:

252.355 Registry of persons with special needs; notice; registration program.—

(1) In order to meet the special needs of persons who would need assistance during evacuations and sheltering because of physical, mental, cognitive impairment, or sensory disabilities, the division, in coordination with each local emergency management agency in the state, shall maintain a

registry of persons with special needs located within the jurisdiction of the local agency. The registration shall identify those persons in need of assistance and plan for resource allocation to meet those identified needs.

(2) In order to ensure that all persons with special needs may register, the division shall develop and maintain a special needs shelter registration program. The registration program must be developed by January 1, 2015, and fully implemented by March 1, 2015.

(a) The registration program shall include, at a minimum, a uniform electronic registration form and a database for uploading and storing submitted registration forms that may be accessed by the appropriate local emergency management agency. The link to the registration form shall be easily accessible on each local emergency management agency's website. Upon receipt of a paper registration form, the local emergency management agency shall enter the person's registration information into the database.

(b) To assist the local emergency management agency in identifying such persons with special needs, home health agencies, hospices, nurse registries, home medical equipment providers, the Department of Children and Families Family Services, the Department of Health, the Agency for Health Care Administration, the Department of Education, the Agency for Persons with Disabilities, the ~~and~~ Department of Elderly Affairs, and memory disorder clinics shall, and any physician licensed under chapter 458 or chapter 459 and any pharmacy licensed under chapter 465 may, annually shall provide registration information to all of their special needs clients or their caregivers and to all persons with special needs who receive services. The division shall develop a brochure that provides information regarding special needs shelter registration procedures. The brochure must be easily accessible on the division's website. All appropriate agencies and community-based service providers, including aging and disability resource centers, memory disorder clinics, home health care providers, hospices, nurse registries, and home medical equipment providers, shall, and any physician licensed under chapter 458 or chapter 459 may, assist emergency management agencies by annually registering persons with special needs for special needs shelters, collecting registration information for persons with special needs as part of the program intake process, and establishing programs to educate clients about the registration process and disaster preparedness safety procedures. A client of a state-funded or federally funded service program who has a physical, mental, or cognitive impairment or sensory disability and who needs assistance in evacuating, or when in a shelter, must register as a person with special needs. The registry shall be updated annually. The registration program shall give persons with special needs the option of preauthorizing emergency response personnel to enter their homes during search and rescue operations if necessary to ensure assure their safety and welfare following disasters.

(c)(2) The division shall be the designated lead agency responsible for community education and outreach to the public, including special needs

clients, regarding registration and special needs shelters and general information regarding shelter stays.

~~(d)(4)~~(a) On or before May 31 of each year, each electric utility in the state shall annually notify residential customers in its service area of the availability of the registration program available through their local emergency management agency by:

1. An initial notification upon the activation of new residential service with the electric utility, followed by one annual notification between January 1 and May 31; or

2. Two separate annual notifications between January 1 and May 31.

~~(b)~~ The notification may be made by any available means, including, but not limited to, written, electronic, or verbal notification, and may be made concurrently with any other notification to residential customers required by law or rule.

(3) A person with special needs must be allowed to bring his or her service animal into a special needs shelter in accordance with s. 413.08.

~~(4)~~(5) All records, data, information, correspondence, and communications relating to the registration of persons with special needs as provided in subsection (1) are confidential and exempt from the provisions of s. 119.07(1), except that such information shall be available to other emergency response agencies, as determined by the local emergency management director. Local law enforcement agencies shall be given complete shelter roster information upon request.

~~(6)~~ All appropriate agencies and community-based service providers, including home health care providers, hospices, nurse registries, and home medical equipment providers, shall assist emergency management agencies by collecting registration information for persons with special needs as part of program intake processes, establishing programs to increase the awareness of the registration process, and educating clients about the procedures that may be necessary for their safety during disasters. Clients of state or federally funded service programs with physical, mental, cognitive impairment, or sensory disabilities who need assistance in evacuating, or when in shelters, must register as persons with special needs.

Section 2. Subsections (3) through (7) of section 381.0303, Florida Statutes, are renumbered as subsections (4) through (8), respectively, paragraph (b) of subsection (2) and present subsection (6) are amended, and a new subsection (3) is added to that section, to read:

381.0303 Special needs shelters.—

(2) SPECIAL NEEDS SHELTER PLAN; STAFFING; STATE AGENCY ASSISTANCE.—If funds have been appropriated to support disaster coordinator positions in county health departments:

(b) County health departments shall, in conjunction with the local emergency management agencies, have the lead responsibility for coordination of the recruitment of health care practitioners to staff local special needs shelters. County health departments shall assign their employees to work in special needs shelters when those employees are needed to protect the health and safety of persons with special needs. County governments shall assist the department with nonmedical staffing and the operation of special needs shelters. The local health department and emergency management agency shall coordinate these efforts to ensure appropriate staffing in special needs shelters, including a staff member who is familiar with the needs of persons with Alzheimer's disease.

(3) SPECIAL CARE FOR PERSONS WITH ALZHEIMER'S DISEASE OR RELATED FORMS OF DEMENTIA.—All special needs shelters must establish designated shelter areas for persons with Alzheimer's disease or related forms of dementia to enable those persons to maintain their normal habits and routines to the greatest extent possible.

(7)(6) RULES.—The department, in coordination with the Division of Emergency Management, has the authority to adopt rules necessary to implement this section. Rules shall include:

(a) The definition of a “person with special needs,” including eligibility criteria for individuals with physical, mental, cognitive impairment, or sensory disabilities and the services a person with special needs can expect to receive in a special needs shelter.

(b) The process for special needs shelter health care practitioners and facility reimbursement for services provided in a disaster.

(c) Guidelines for special needs shelter staffing levels to provide services.

(d) The definition of and standards for special needs shelter supplies and equipment, including durable medical equipment.

(e) Standards for the special needs shelter registration program process, including all necessary forms and guidelines for addressing the needs of unregistered persons in need of a special needs shelter.

(f) Standards for addressing the needs of families where only one dependent is eligible for admission to a special needs shelter and the needs of adults with special needs who are caregivers for individuals without special needs.

(g) The requirement of the county health departments to seek the participation of hospitals, nursing homes, assisted living facilities, home health agencies, hospice providers, nurse registries, home medical equipment providers, dialysis centers, and other health and medical emergency preparedness stakeholders in pre-event planning activities.

Section 3. Section 381.82, Florida Statutes, is created to read:

381.82 Ed and Ethel Moore Alzheimer’s Disease Research Program.—

(1) The Ed and Ethel Moore Alzheimer’s Disease Research Program is created within the Department of Health. The purpose of the program is to fund research leading to prevention of or a cure for Alzheimer’s disease. The long-term goals of the program are to:

(a) Improve the health of Floridians by researching better prevention and diagnoses of and treatments and cures for Alzheimer’s disease.

(b) Expand the foundation of knowledge relating to the prevention, diagnosis, treatment, and cure of Alzheimer’s disease.

(c) Stimulate economic activity in the state in areas related to Alzheimer’s disease research.

(2)(a) Funds appropriated for the Ed and Ethel Moore Alzheimer’s Disease Research Program shall be used exclusively for the award of grants and fellowships through a competitive process for research relating to the prevention, diagnosis, treatment, and cure of Alzheimer’s disease and for expenses incurred in the administration of this section. Priority shall be granted to research designed to prevent or cure Alzheimer’s disease.

(b) Applications for Alzheimer’s disease research funding under the program may be submitted from any university or established research institute in the state. All qualified investigators in the state, regardless of institution affiliation, shall have equal access and opportunity to compete for research funding. The following types of applications may be considered for funding:

1. Investigator-initiated research grants.
2. Institutional research grants.
3. Predoctoral and postdoctoral research fellowships.
4. Collaborative research grants, including those that advance the finding of cures through basic or applied research.

(3) There is created within the Department of Health the Alzheimer’s Disease Research Grant Advisory Board.

(a) The board shall consist of 11 members appointed by the State Surgeon General. The board shall be composed of two gerontologists, two geriatric psychiatrists, two geriatricians, two neuroscientists, and three neurologists. Initial appointments to the board shall be made by October 1, 2014. The board members shall serve 4-year terms, except that, to provide for staggered terms, five of the initial appointees shall serve 2-year terms and six shall serve 4-year terms. All subsequent appointments shall be for 4-year terms. The chair of the board shall be elected from the membership of the board and shall serve as chair for 2 years. An appointed member may not serve more

than two consecutive terms. Appointed members must have experience in Alzheimer's disease or related biomedical research. The board shall adopt internal organizational procedures as necessary for its efficient organization. The board shall establish and follow rigorous guidelines for ethical conduct and adhere to a strict policy with regard to conflicts of interest. A member of the board may not participate in any discussion or decision of the board or a panel with respect to a research proposal by any firm, entity, or agency with which the member is associated as a member of the governing body or as an employee or with which the member has entered into a contractual arrangement.

(b) The department shall provide such staff, information, and other assistance as is reasonably necessary to assist the board in carrying out its responsibilities. Members of the board shall serve without compensation and may not receive reimbursement for per diem or travel expenses.

(c) The board shall advise the State Surgeon General as to the scope of the research program and shall submit its recommendations for proposals to be funded to the State Surgeon General by December 15 of each year. Grants and fellowships shall be awarded by the State Surgeon General, after consultation with the board, on the basis of scientific merit. Other responsibilities of the board may include, but are not limited to, providing advice on program priorities and emphases; assisting in the development of appropriate linkages to nonacademic entities, such as voluntary organizations, health care delivery institutions, industry, government agencies, and public officials; and developing and providing oversight regarding mechanisms for the dissemination of research results.

(4) The board shall submit a fiscal-year progress report on the programs under its purview annually to the Governor, the President of the Senate, the Speaker of the House of Representatives, and the State Surgeon General by February 15. The report must include:

(a) A list of research projects supported by grants or fellowships awarded under the program.

(b) A list of recipients of program grants or fellowships.

(c) A list of publications in peer-reviewed journals involving research supported by grants or fellowships awarded under the program.

(d) The state ranking and total amount of Alzheimer's disease research funding currently flowing into the state from the National Institutes of Health.

(e) New grants for Alzheimer's disease research which were funded based on research supported by grants or fellowships awarded under the program.

(f) Progress toward programmatic goals, particularly in the prevention, diagnosis, treatment, and cure of Alzheimer's disease.

(g) Recommendations to further the mission of the program.

(5) The activities of the board provided in subsection (3) are exempt from chapter 120.

(6) The department may adopt rules as necessary to implement the provisions of this section.

(7) Implementation of the Ed and Ethel Moore Alzheimer’s Disease Research Program is subject to legislative appropriation.

Section 4. Subsections (3) through (9) of section 430.502, Florida Statutes, are renumbered as subsections (6) through (12), respectively, new subsections (3), (4), and (5) are added to that section, and paragraph (e) of subsection (1) and present subsections (4), (5), (8), and (9) of that section are amended, to read:

430.502 Alzheimer’s disease; memory disorder clinics and day care and respite care programs.—

(1) There is established:

(e) A memory disorder clinic operated by Health First The Memory Disorder Clinic, Inc., operating in Brevard County;

(3) The department shall develop minimum performance standards for memory disorder clinics and include those standards in each memory disorder clinic contract as a condition for receiving base-level funding. The performance standards must address, at a minimum, quality of care, comprehensiveness of services, and access to services.

(4) The department shall develop performance goals that exceed the minimum performance standards developed under subsection (3), which goals must be achieved in order for a memory disorder clinic to be eligible for incentive funding above the base level, subject to legislative appropriation. Incentive funding shall be based on criteria including, but not limited to:

(a) Significant increase in the volume of clinical services.

(b) Significant increase in public outreach to low-income and minority populations.

(c) Significant increase in acceptance of Medicaid and commercial insurance policies.

(d) Significant institutional financial commitments.

(5) The department shall measure and score each memory disorder clinic based on minimum performance standards and incentive performance goals.

(7)(4) Pursuant to the provisions of s. 287.057, the department of Elderly Affairs may contract for the provision of specialized model day care programs

in conjunction with the memory disorder clinics. The purpose of each model day care program must be to provide service delivery to persons suffering from Alzheimer’s disease or a related memory disorder and training for health care and social service personnel in the care of persons having Alzheimer’s disease or related memory disorders.

~~(8)~~(5) Pursuant to s. 287.057, the department of ~~Elderly Affairs~~ shall contract for the provision of respite care. All funds appropriated for the provision of respite care shall be distributed annually by the department to each funded county according to an allocation formula. In developing the formula, the department shall consider the number and proportion of the county population of individuals who are 75 years of age and older. Each respite care program shall be used as a resource for research and statistical data by the memory disorder clinics established in this part. In consultation with the memory disorder clinics, the department shall specify the information to be provided by the respite care programs for research purposes.

~~(11)~~(8) The department shall implement the waiver program specified in subsection ~~(10)~~ (7). The agency and the department shall ensure that providers who have a history of successfully serving persons with Alzheimer’s disease are selected. The department and the agency shall develop specialized standards for providers and services tailored to persons in the early, middle, and late stages of Alzheimer’s disease and designate a level of care determination process and standard that is most appropriate to this population. The department and the agency shall include in the waiver services designed to assist the caregiver in continuing to provide in-home care. The department shall implement this waiver program subject to a specific appropriation or as provided in the General Appropriations Act.

~~(12)~~(9) Authority to continue the waiver program specified in subsection ~~(10)~~ (7) shall be automatically eliminated at the close of the 2010 Regular Session of the Legislature unless further legislative action is taken to continue it before ~~prior to~~ such time.

Section 5. This act shall take effect July 1, 2014.

Approved by the Governor June 18, 2014.

Filed in Office Secretary of State June 18, 2014.